

Care in the last days of life

Information for patients, relatives and carers

This leaflet outlines some of the physical changes that can occur in the last days and hours of life. It also describes the way in which we will support individuals in the last days of life, and their loved ones. It anticipates some of the questions you may want to ask about what is happening and why, and encourages you to ask for further help or information if there is anything worrying you.

Developing a plan of care

When a person is recognised to be in the last days and hours of life, doctors and nurses will develop, in agreement with the person and their loved ones, an individualised plan to support their treatment and care. This plan is called a care agreement and documents decisions regarding treatment and care alongside patient's and loved ones' wishes. It is important to know that all treatment decisions are carefully considered and the balance of benefit versus harm is weighed up for each individual person. Treatments where there is considered to be more harm than benefit are unlikely to be given. The care agreement will be reviewed regularly by the healthcare team looking after the person and they will ensure comfort and dignity are prioritised at all times.

At all times, our aim is to communicate openly with the person and their loved ones. If you feel we have not explained things clearly or if you do not feel you have been involved in the necessary conversations then please let your doctor or nurse know.

What to expect when a loved one is dying

The experience of dying is unique to each individual but there are common characteristics or changes that we may expect to see in the last days and hours. These fall into four main categories:

- reduced need for food and drink
- changes in level of alertness
- changes in breathing
- changes in the last hours

Reduced need for food and drink

People will be encouraged and supported to eat and drink for as long as possible but when someone starts to die, their body no longer has the same need for food and drink as before. The body's metabolism slows down and food is no longer digested well. Usually this is a gradual process, beginning with a reduction in volume of food tolerated, progressing through sips of fluid to the point when a dying person may not be able to eat or drink at all. When people stop drinking completely, although their mouth may look dry, it's not a sign that they are dehydrated. Gently moistening the mouth with a damp sponge and applying lip salve will give comfort.

It can be hard to accept a person's lack of interest in food and drink even when you know that the person is dying, as it's a physical sign that they are not going to get better. Nevertheless, you can still support your loved one by offering them food and drink for pleasure and comfort when they wish it. We will offer you advice on the safest way to do this for your loved one.

Changes in level of alertness

For most, as someone starts to die, changes in level of alertness happen gradually. People spend more and more time asleep and when they are awake they are often drowsy and show less interest in what is going on around them. Despite being less alert, hearing the familiar voices of family and friends at this time can be reassuring and comforting. It is important that family and friends, in pairs or small groups, are able to spend more time with loved ones as they are dying.

Changes in breathing

Towards the end of life, as the body becomes less active, the demand for oxygen lessens. People who suffer from breathlessness are often concerned that they may die fighting for breath but, in fact, breathing eases as they enter the last days of life.

Breathing problems can be made worse by feelings of anxiety but the knowledge that someone is close at hand is reassuring. Sitting quietly and holding your loved one's hand can make a real difference.

Occasionally in the last hours of life breathing can sound noisy or have a rattle sound. This is due to a build-up of secretions in the person's airways which they are no longer able to swallow or cough up. Medication may be used to reduce the build-up and changes of position may also help. The noisy breathing can be upsetting to family and friends but it doesn't appear to distress the dying person.

Changes in the last hours

When death is very close (within hours or minutes) the breathing pattern may change. Sometimes there are long pauses between breaths or the abdominal muscles (tummy) will take over the work, so the tummy rises and falls instead of the chest. Breathing may appear more laboured but is unlikely to cause distress to the dying person at this stage. The dying person will be closely monitored throughout to ensure they are comfortable.

Occasionally, people may become more agitated as death approaches. If this happens staff on the ward will assess your loved one and talk to you about it. They will ensure that pain and other symptoms are well-controlled and give sedating medication to help them relax where appropriate.

If your religion or culture has particular rituals that should be performed near the time of death, please consider making arrangements for these to take place as these changes are happening.

The skin can become pale and moist and slightly cool before death.

Most people do not wake from sleep but die peacefully, comfortably and quietly.

What happens after a person has died?

After a person has died the nurses will wash and prepare the body on the ward before transfer to the mortuary. Loved ones can help with this - please let your nurse know if you would like to do so. If there are specific faith or religious requirements regarding care of the body after death, e.g. washing for religious purposes, these should take place at a place of worship or funeral directors who are equipped to do this in line with religious requirements.

Once the body has left the ward, contact details for the next of kin will be given to the bereavement office. The bereavement office will contact the next of kin on the working day following the death to discuss next steps. These steps routinely involve the Medical Examiner service; a team of independent senior clinicians who examine all deaths and will confirm the cause of death with the next of kin. Further information on the next steps can be found in our bereavement leaflet.

How we can help

This is likely to be a difficult and painful time for you as you lose someone you love or have cared for. It can be hard to know what to say, how to help or what to do. Nurses, doctors and other staff are there to help you work through your worries and concerns and to offer you care and support. We hope that you will talk to us if there is anything on your mind.

Additional information and support

Chaplaincy service

The chaplaincy team is made up Anglican, Jewish, Muslim, and Roman Catholic chaplains and has contacts in the community to provide for the needs of other religious communities. The team is happy to make contact with and arrange a visit by a representative of a community known personally to the patient or those who are close to them.

We offer confidential religious, spiritual and pastoral care to all patients and visitors between 09.00 and 17.00 with a 24/7 urgent out-of-hours on-call service. To request a visit, speak to a member of your care team and ask them to contact the on-call chaplain. Patients can also call directly on **020 3312 1508** where you can leave a message but please be aware you may not receive a response until the next working day.

Interpreting services

Discussions and decisions about treatment options can be challenging, especially if English is not your first language or if you don't have good support networks. If you need a language or British Sign Language interpreter please let your care team know and they will organise this for you.

Patient advice and liaison service (PALS)

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: **020 3312 1337 / 1349**

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information visit our website: www.imperial.nhs.uk

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Trust-wide
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